

Analytic principles for patient-reported outcome measures

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Preface

NSW Health has embarked on a system-wide transformation to value based healthcare. A defining part of value based healthcare is understanding and responding to 'what matters most' to patients. This requires the systematic collection and use of patient reported measures. These measures are a direct account of patients' experiences of care, perceptions about their health status or about how treatment affects their general well-being and ability to do the things that are important to them.

The systematic measurement of outcomes, using both clinical and patient-reported data, ensures a focus on maximising 'what matters' from the perspective of the person receiving care, not just those providing or funding it. It can inform care planning between patients and clinicians, evaluate the impact of care, improve care delivery, and guide resource allocation and policy decisions.

Drawing on patient insights is not a new idea and methods for analysing patient experience data are well established. However, questions about how best to analyse, synthesise, infer and generalise from patient-reported outcome data are not yet fully resolved. This situation, together with the introduction of the Health Outcomes and Patient Experience (HOPE) system into NSW Health, has prompted the production of this report. HOPE will deliver a reliable stream of patient-reported data to decision-makers in NSW Health – complementing existing data sources.

Patient-reported outcome measures have the potential to fundamentally shape practice. They enable clinicians to better engage with their patients – facilitating discussions about what matters most – do they have pain? Is that pain preventing them from activities that are important to them? Are there trade-offs they would like to make between pain and side-effects? Patient-reported measures also provide opportunities for

clinicians to reflect on how the outcomes have been achieved – in light of trends or comparative data from other clinicians' patients – and to catalyse change and improvement.

This is a technical report – its main audience comprises analysts, managers or clinicians who will examine, evaluate, summarise and interpret patient-reported outcome data – either unlinked data such as that collected via the HOPE system, or linked data held in the Registry of Outcomes, Value and Experience (ROVE). The report outlines guiding principles – based on current knowledge about appropriate techniques and methods – to underpin and inform analyses, and ensure the validity and reliability of patient-reported outcome data. It does not provide a detailed analytic plan or step-by-step operational guide. The principles outlined in the report have been articulated in anticipation of HOPE but most of the issues are relevant with other similar sources of patient-reported measures.

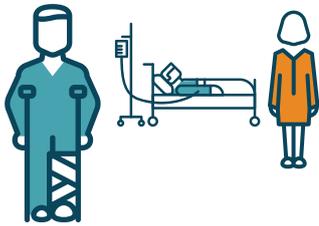
Efforts are underway at individual, clinic, hospital, regional and system levels to use data collected by patient-reported measures – to guide clinical decisions, reflect on quality, evaluate performance, drive improvement and secure better value care. End users will indirectly benefit from the principles outlined in this document and many may be interested in understanding the challenges in interpreting patient-reported outcome measures. To help meet these challenges, the report includes a series of personas which illustrate the ways in which different users can confidently and appropriately use the data.

The report represents a first step in realising the potential of patient-reported outcome measures. It outlines how a phased approach could result in timely provision of patient health status data and descriptive analyses in the short term, with more complex evaluation and time series approaches developed in the longer term.

Key analytic principles for patient-reported outcome measures

Patient-reported measures assess health-related quality of life, functional status, symptoms and symptom burden, treatment burden, health behaviours and health status.

For robust assessments and conclusions, analyses take account of patient characteristics, time, data quality and fair comparisons.



1. Patient characteristics

How to interpret patient-reported data across different case complexities, cognitive capacities, social circumstances.

Especially important for:

- populations in integrated care programs
- patients with impaired cognitive capacity such as hip fracture patients.



2. Time

What represents a meaningful change in patient-reported outcomes.

How to interpret improvement and worsening, of individual and aggregated data.

Especially important for:

- patients with chronic diseases such as chronic obstructive pulmonary disease, congestive heart failure, rheumatoid arthritis.

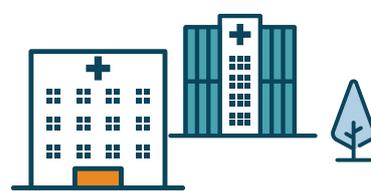


3. Data quality

- Underlying reasons and impact of missing responses and questionnaires
- Metadata-based insights to assess completion.

Especially important for:

- older, sicker patients who may be less likely to fill questionnaires, creating a bias.



4. Fair comparisons

How to adjust for differences in case mix, patient resilience, environmental confounders, utilisation patterns.

Especially important for:

- benchmarking and peer comparisons of clinicians, clinical teams, hospitals.

Summary

The systematic collection of patient-reported outcome data brings new opportunities for analysis and insights for clinical, organisational and system decision-makers in NSW.

This document outlines key principles to guide analysis of patient-reported outcome data, such as those collected by the Health Outcomes and Patient Experience (HOPE) system. The principles will provide guidance for local analytic plans and help ensure that what patients tell us about their health and outcomes is interpreted accurately.

Three key dimensions should be considered in formulating an analytic plan for patient-reported outcome measures – the type of data that are

collected, the proposed application, and potential users (Table 1).

For each combination of data type, application and user, foundational investigations and analyses should demonstrate and assure that inferences or interpretation of the data are reliable, accurate, precise and fair. This document outlines the main areas of work that can provide that assurance. Not all steps are required at the outset, and a stepped approach can be adopted.

NSW Health has defined primary and secondary uses of patient-reported data. Primary use supports real-time decisions by clinicians and patients. Secondary use supports reflective practice, evaluation, policy and predictive modelling applications. Key foundational analytic requirements are summarised in Table 2.

Table 1: Dimensions considered in the analytic principles

Dimensions	Types
Different types of patient-reported outcome data*	<ul style="list-style-type: none"> • Symptoms and symptom burden • Treatment burden • Health-related quality of life • Functional status • Health behaviours
Different applications or uses of data (see Table 2)	<ul style="list-style-type: none"> • Real-time (synchronous) clinical and shared decision making using contemporaneous data • Real-time (synchronous) clinical and shared decision making informed by aggregated and population data (alerts/predictive algorithms/diversion from expected trajectory/risk profiles) • Asynchronous identification of data patterns, cohorts and support for reflective clinical practice • Asynchronous evaluation and organisational management and monitoring • System-level policy and planning
Different users	<ul style="list-style-type: none"> • Individual patients • Individual clinicians • Clinical teams • Service managers or organisations • District planners • System architects and policy makers

* Only when data collection includes two or more time points is it possible to measure outcomes.

Patient-reported experience measures are also collected by the HOPE system, however methods and analyses for experience measures are well established and are not considered in this report. The collection, storage, utilisation and analysis of data from private companies is out of scope.

Table 2: Foundational analytic requirements	Primary use		Secondary use			Analytic development phases
	Real-time clinical	Real-time predictive	Reflective practice	Evaluation and management	System policy	
Before use, steps highlighted below should be completed						
Data quality assurance checks	●	●	●	●	●	1
Assessment (and reassessment) of individual measures (acceptability, relevance, reliability, responsiveness, accuracy) and interpretation	●	●	●	●	●	
Assessment of impact of data collection setting and mode (e.g. in waiting room vs at home) as potential bias	●	●	●	●	●	
Definition of outliers and cut-off points for interpretation	●	●	●	●	●	
Definition of inclusion and exclusion criteria		●	●	●	●	2
Definition of timing for treatment, measurement, attribution for different conditions		●	●	●	●	
Definition and calibration of statistical and clinical significance of results		●	●	●	●	
Establishment of processes to assess missing data (e.g. missing items, missing questionnaires, randomness of missing items)		●	●	●	●	
Assessment of patterns of non-response (e.g. for ability of patients to participate and effect of literacy, dementia, etc.)		●	●	●	●	
Assurance of validity of time series (e.g. attrition rates, response shift, imputation, minimally important differences, ceiling effects)		●	●	●	●	
Assessment of benefits of linkage with patient utilisation history		●	●	●	●	
Assurance of validity of comparative analyses (e.g. patient groups, professionals, hospitals)			●	●	●	
Assessment of the appropriate use of patient factors in adjustment (e.g. socio-economic status, resilience)			●	●	●	3
Assessment of the use of propensity matching techniques for attribution of outcomes			●	●	●	
Assessment of validity, sensitivity and specificity of changes in measures over time				●	●	
Data triangulation to strengthen attribution				●	●	
Assessment of potential confounders (e.g. principal diagnoses, social circumstances, time since diagnosis, emotional state, patient trajectories)				●	●	
Definition of attribution decision rules (e.g. multiple visits, intervals, multiple teams)				●	●	
Assessment of validity for economic evaluation, quality adjusted life year analyses				●	●	
Validation of predictive algorithms		●				4

Introduction

The systematic collection and use of patient-reported measures (PRMs) is key to realising NSW Health's vision for truly integrated and better value care for the state's population.^{1,2}

The introduction of the systematic collection of patient-reported data will bring significant opportunities for data analysis, and the development of new and important insights for clinical, organisational and system decision-makers.

However, a series of data validation processes and analytic sensitivity analyses are needed before it is possible to meaningfully use the data collected. A deliberate and considered set of guiding principles is required to ensure that any inferences made from patient data are valid, reliable and robust, and to provide confidence in the interpretation of what patients report about their health, symptoms, quality of life and the things that matter to them.

Why do we need guiding principles?

The NSW healthcare system has decades of experience with data from administrative surveys, patient experience surveys and clinical registry datasets – with established protocols and standards to guide practice and significant analytic expertise distributed around the state. In contrast, patient-reported outcome measures have less established analytic foundations and communities of practice.

NSW is not unique in this regard. While patient-reported outcome measures have been widely used in discrete research projects, very few healthcare systems have built the analytic capacity to fully leverage the potential of patient-reported measures.

The widespread research-based applications have resulted in many validated tools for the collection of patient-reported outcome measures. However, there is a lack of well validated, standardised approaches to compare outcomes between healthcare providers for understanding time series data or interpreting data relative to patients' trajectories or disease progression. This lack of shared understanding poses considerable risk of over- and under-interpretation of data, missed opportunities to respond to and learn from patients' perspectives, damaged reputations and missteps in action and policy.

This document outlines the key elements that a data analytic plan should consider and proposes a phased approach to developing a robust platform for analyses of patient-reported measures in NSW.

Data and methods

The information in this document is drawn from three key sources.

1. Peer reviewed literature – a PubMed search (“patient reported measures” [ti/ab] OR patient reported outcome” [ti/ab]) AND “data analytic”[MeSH].
2. Grey literature search of key health organisations.
3. Expert working group comprised of experts from policy, delivery and across primary and hospital sectors (Appendix 1).

What are patient-reported outcome measures?

Patient-reported outcome measures collect data on biological, psychological and social parameters and are used to subjectively assess health status and wellbeing. They are particularly valuable in providing an assessment of characteristics, which are difficult or impossible to measure physically, such as pain, depression, fatigue, quality of life, or self-efficacy.

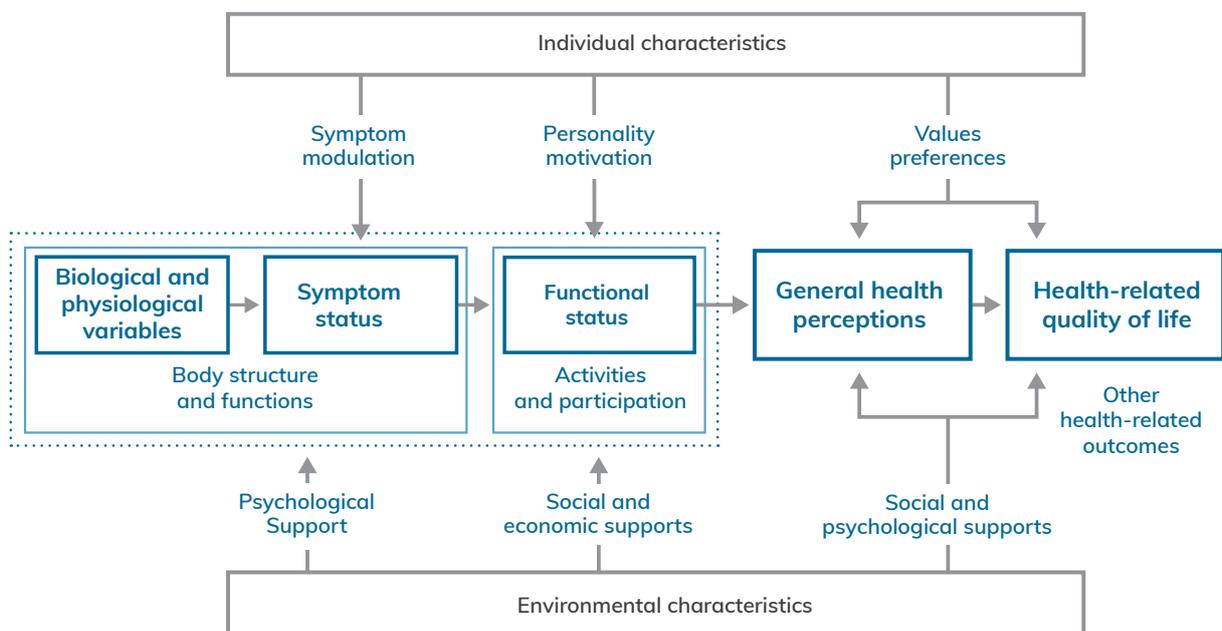
They are also used to collect information about symptoms such as vomiting, sleeplessness or dyspnoea, which could be physically measured, but with more difficulty or measurement error (Figure 1).

Patient-reported outcome measures provide a way to capture patients' voices and utilise them – as both an input to care, shaping shared clinical decision-making, and as an outcome of care, reflecting on performance and quality (Table 3).

Table 3: Patient-reported measures used as inputs to – and outcomes of – care

As an input to care
<ul style="list-style-type: none"> • Biometric data • Health status • Symptoms • Physical function • Patient needs • Patient goals, values and preferences • Patient engagement and activation.
As an outcome of care
<p>With two time points:</p> <ul style="list-style-type: none"> • outcomes of care – physical, functional, emotional, quality of life • patient knowledge, confidence and self-efficacy.

Figure 1: Different types of patient reported outcome data



Source: Adapted from Mayo et al, 2017.³

Data collection

Data collection for patient-reported outcomes is generally in the form of either paper-based or digital questionnaires, consisting of items (questions) grouped into one or more subscales (domains), which aim to measure an underlying construct.

In NSW, the HOPE system will use digital data collection and the data will feed into integrated and linked datasets, providing important information for decision-making at an individual, service and system level (Table 4).

The NSW Health Data Governance Framework⁴² asserts that it is the responsibility of local data stewards and data users to ensure the quality of the data capture and completeness of variables. The centralised data steward assists and provides support and advice to local teams.

The Framework outlines roles, responsibilities and appropriate primary and secondary use of data. In addition, the Ministry of Health's prioritisation framework guides incorporation of new patient groups, inclusion in the HOPE system, and the information available to different audiences.

Table 4: Potential contribution of patient-reported outcome measures at an individual, organisational and system level

Decision-making level	Potential contribution of patient-reported outcome measures
Individual	<ul style="list-style-type: none"> • Understand and enhance interactions between patients and their care providers • Support shared decision-making regarding care, treatment and/or interventions • Provide data back to patients for individual use and record keeping
Service	<ul style="list-style-type: none"> • Compare outcomes across patient populations, cohorts, providers, teams, wards or services • Assess utilisation patterns, efficacy of interventions or treatments, and links between processes and outcomes • Clinical modelling, evaluation and priority setting analyses
System	<ul style="list-style-type: none"> • Inform policy • Reveal trends in outcomes • Identify factors associated with value based healthcare • Inform quality improvement decisions at a state level • Assess adherence to clinical guidelines • Measure performance across healthcare organisations and services

Source: Adapted from Williams et al, 2016.⁴

Data governance and management context

The analytic principles outlined in this report align with the NSW Health vision, the *Patient Reported Measures Data Governance and Management Framework* (the PRMs Framework)⁴³ which outlines the principles and arrangements for the NSW health system to ensure effective management and governance of the data held by the HOPE system. The PRMs Framework guides the effective management and governance of data assets through the exercise of authority and control in planning, guiding and monitoring activities.

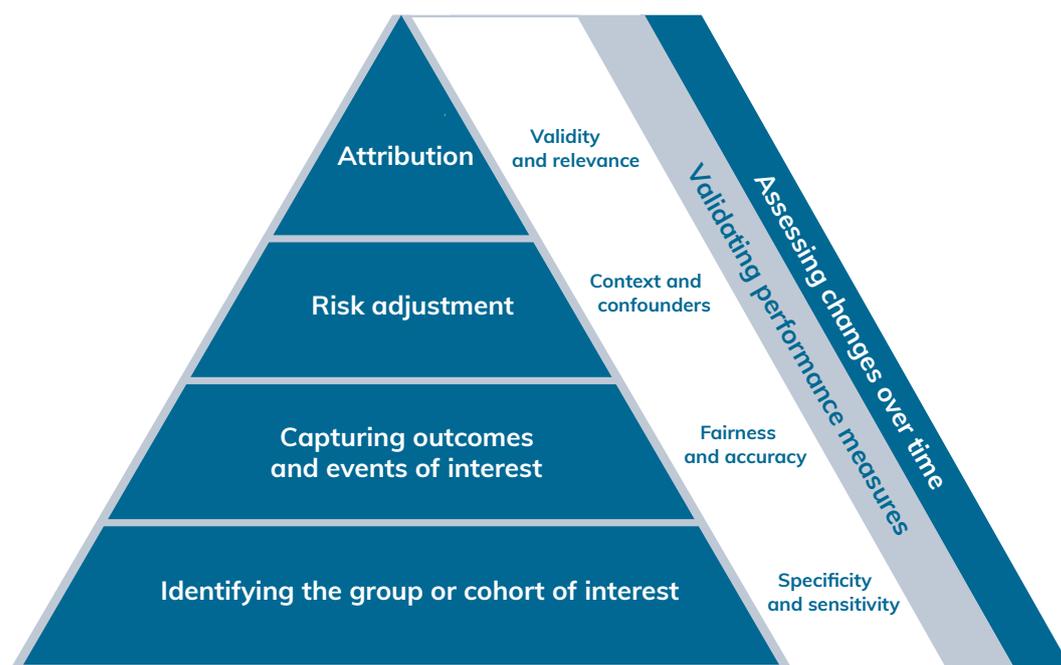
This report draws on established approaches to metric development. It addresses cohort definition, identification of outcomes of interest, risk adjustment, attribution and validation and temporal analyses (Figure 2).

The report is structured using specific themes from the following topics:

- ensuring measures are fit for purpose
- assessment of individual measures or measurement tools
- data quality assessment
- identifying the group of interest and assuring data capture
- measuring outcomes and sensitivity to change
- longitudinal analyses: timing of data collection, and missing data
- confounders – patient trajectories and complexity
- metadata
- phased approach – proposed timelines.

The information is contextualised with four personas that describe how clinicians, analysts and managers can use the data emanating from the HOPE system.

Figure 2: Metric development and data analytic approach



Source: Bureau of Health Information, 2015.⁵

Ensuring measurement tools are fit for purpose

Patient-reported outcome measures can assess health status, health-related quality of life, symptoms and function (Table 5). They can be used as one-off indicators, or to assess outcomes if they are collected at two or more time points.

There is a vast array of tools available. The selection of tools and the timing of use should be guided by the overarching aims and objectives of measurement, and characteristics of the target population and their disease trajectories.⁶

Patient engagement and co-design in identifying 'measures that matter' is a key consideration.

NSW Health in establishing its PRM program assessed the validity, interpretation and feasibility of various tools for nominated patient groups across NSW. The program secured endorsement from clinical groups and networks to ensure measures were fit for purpose.

Table 5: Types of patient-reported outcome data – contributions and limitations

Patient-reported outcome data	Contribution	Limitations and potential biases
Health-related quality of life	Provide a summary of wellbeing, encompassing physical, psychological and social elements associated with illness and its treatment.	Can lack sensitivity to disease specific issues if a generic Health Related Quality of Life (HRQoL) measure is used and the assessment framing is 'global' (e.g. how was your quality of life in the past week). Tools with no population weights have limitations in system evaluation applications. There are however, many condition-specific HRQoL measures available.
Functional status	Reflects ability to perform specific, and important, activities. Can be used in addition to performance-based tests (e.g. range of movement). This is often 'what matters' to patients.	There may be differences between self-reported capability and actual capability.
Symptoms and symptom burden (or treatment burden)	Can provide data on symptom intensity, impact, frequency and duration as well as identify symptoms not captured by medical workup.	May fail to capture general global aspects of wellbeing. Patients may intentionally under- or over-report the degree or level of symptom experience in order to influence a clinical decision in favour of their preferred decision outcome.
Health behaviours	Provide insight into frequency of particular behaviours, information often not otherwise available.	May be affected by social desirability.

Source: Adapted from Cella et al, 2015.⁷

Generic or specific tools

Generic patient-reported measures (e.g. SF-36, or PROMIS-29) gauge factors such as health status or quality of life that are common to most patients. Specific tools capture more detailed information about symptoms and trajectories of treatment and recovery.

The advantage of generic tools is that they allow comparison of outcomes across conditions. Condition-specific tools are generally more sensitive to changes over time than generic patient-reported outcome measures (PROMs).⁸⁻¹⁰ Specific measures can underestimate the effect of multimorbidity, which is often associated with suboptimal care, longer hospital stays, frequent use of healthcare, and an elevated risk of adverse events and errors.

When used together, generic and disease-specific PROMs can provide complementary information. When choosing a generic and condition-specific pair, it is important to avoid overlap of content as this

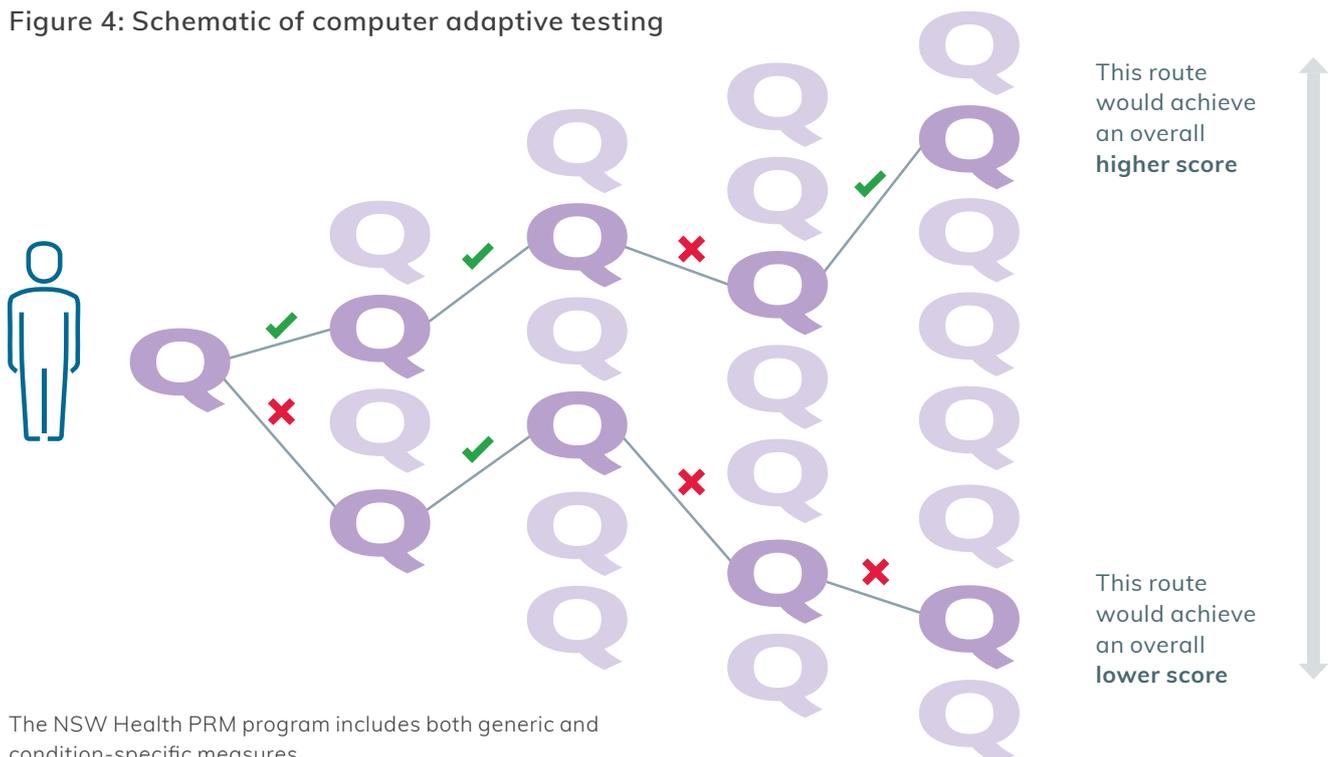
is inefficient at all levels of data usage (inherent redundancy and correlation), and causes unnecessary patient burden and annoyance.

In NSW, the EQ-5D instrument will be used to support economic analyses and PROMIS-29 will support clinical decision-making.

Dynamic tools

Computer adaptive testing is a method that can be used in surveying and testing applications, and has been used with PROMIS tools. Drawing on item response theory, the approach tailors question sets so that each response determines the next question to be asked (Figure 4).¹¹ This means that patients are given the minimum number of items necessary, through statistical inference, to determine their final score – reducing respondent burden.

Figure 4: Schematic of computer adaptive testing



The NSW Health PRM program includes both generic and condition-specific measures.

Assessment of individual measures or measurement tools

Selection of an appropriate measure is underpinned by assessment of core attributes (Table 6), considered in a local context.

Three criteria – reliability, validity and responsiveness – are generally considered to be the most important attributes and require periodic reassessment.

Patient-reported measures that are in widespread use are generally supported by published information about the core attributes.

Local application requires consideration of these characteristics in light of local circumstances and objectives.

Clear documentation, which defines scoring and guides users in interpreting scores, is essential. This should outline what low and high scores represent for the measured concept, what constitutes an outlier result, and distinguish statistical significance from clinical significance.¹²

Table 6: Attributes of patient-reported measures which require assessment

Construct	Assessment criteria	Periodic reassessment
Concept	The construct to be measured by the tool is clearly stated.	
Reliability	The tool yields the same score each time it is administered (all other things being equal). Assessments consider internal consistency (similarly themed item scores are correlated) and the test and retest reliability (the same results are achieved if the tool is re-administered).	●
Validity	The tool measures what it claims to measure. Different subtypes of validity include content, construct, criterion, concurrent, convergent, discriminant.	●
Responsiveness	The tool is able to detect change over time.	●
Interpretability	The meaning of results or scores is easily understood.	
Burden	The tool is relatively straightforward and easy to administer and use.	
Mode of administration	The feasibility of different options for collecting data – face-to-face, telephone, tablet or mixed methods and their potential to introduce bias is minimal.	●
Cross-cultural, linguistic, literacy age, gender appropriateness	The tool is available or adaptable for use in different patient groups.	

Adapted from: Francis et al, 2016; Sansoni, 2018; and Valderas 2008.

Snapshot: Generic tool endorsed for use in NSW – patient-reported outcomes measurement information system (PROMIS)

PROMIS tools were developed in the United States (US) to be ‘disease non-specific’ measures of health-related domains. PROMIS-29 assesses seven health-related domains: depression; anxiety; physical function; pain interference; fatigue; sleep disturbance; and ability to participate in social roles and activities.

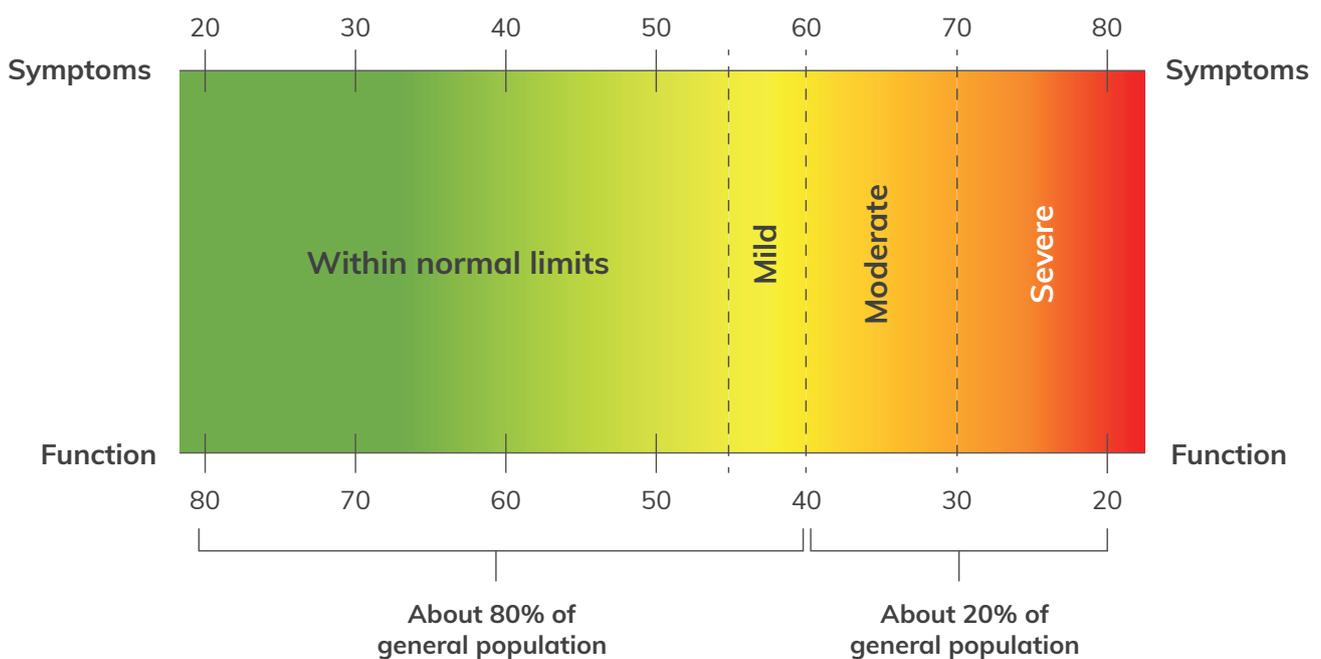
Each domain is composed of an item bank – assessed with four questions ranked by patients on a five-point Likert scale. The higher the domain score, the more of the concept being measured (i.e. more physically able; more anxious, etc.). There is also one 11-point rating scale (0-10) for pain intensity.

Raw scores are transformed to standardised T-score metrics, with a mean of 50 and standard deviation of 10 (Figure 3). Calculation of T-scores is based on the US population in 2000. Validity of the item banks is assessed through the use of item response theory, and is an ongoing iterative process.

PROMIS-29 has a T-score conversion table for each domain. T-scores cannot be aggregated across domains. Raw scores for individual questions should not be used. For pain intensity, there is no T-score and the raw score is used (0-10). If any items are missing (i.e. questions are not answered), the domain score cannot be calculated.

Cook, et al., conducted a review demonstrating the validity and appropriateness of PROMIS measures across varied clinical populations.¹³

Figure 3: PROMIS-29 T-scores – non-specific measurement of health related domains



*These are general guidelines to aid an interpreting PROMIS T-scores. Within a given condition or PROMIS domain, thresholds may differ.

Data quality assessment

Robust data quality assessment forms the foundation for any analytic plan.

Sound data stewardship requires assessment and documentation of seven key constructs (Table 7).

Data stewards are responsible for these assessments at a system level, and at a local, level where necessary.

Table 7: Data quality assessment constructs

Construct	Quality assessment questions
Institutional environment	Which organisation(s) collect the data? What authority, legislation or agreement is the data collected under? Is statistical confidentiality guaranteed, and if so, under what authority or legislation? To what extent and how quickly are any identified errors in published statistics corrected and publicised?
Relevance	About whom, or what, was the data collected? At what levels of geography are data available? What key data items are available? If rates and percentages have been calculated, are the numerators and denominators for the same data source(s)? If not, please provide more information.
Timeliness	How often are the data collected? What is the reference period for the data?
Accuracy	How are the data collected? Have the data been adjusted in any way? If so, how much was adjusted and on what data items? What is the sample size? What is the collection size? What are the standard errors for the key data items? Are there known issues with under-counts or over-counts? Are there sensitive questions or topics that are collected that may cause bias? What steps have been taken to minimise processing errors? What are the non-response, non-reporting, or item non-reporting rates? Are any parts of the population unaccounted for in the data collected?
Coherence	How consistent are the data over time? If the data for the quality statement are based on a percentage or rate, how do the numerator and denominator compare with each other? What are the differences which affect their comparability? Have there been changes to the underlying data collection? Have any real-world events impacted on the data since the previous release? How have these impacts on the data been managed? What other data sources is this data comparable with? How do these data sources compare?
Interpretability	Is there a particular context that this data needs to be considered within? Are there any ambiguous or technical terms that may need further explanation?
Accessibility	In which formats are the data available for people to use? Where and how do you access them? Are there any privacy or confidentiality issues that prevent the data from being released publicly?

Adapted from ABS Data Quality Statements.¹⁴

Responsibilities for this will be articulated in future analytic plans. New users to existing datasets can consult minimum dataset definitions to inform these assessments. New data collections, in contrast, require the production and publication of definitions.

Prior to any data analysis, several routine tasks are necessary. They include data screening for:

- skewed distributions and missing data
- association between variables
- bias associated with the mode of data collection
- identification and correction of data errors (Table 8).

An important assessment technique specific to surveys is differential item functioning (DIF) and the identification of benign and adverse DIF. Benign DIF reflects real group differences in an underlying trait or attribute (e.g. women are more concerned about urinary incontinence than men), while adverse DIF reflects bias in the measurement process (e.g. groups interpret the meaning or the item differently).

Table 8: Sources of error in data

Source for error detection	Examples
Inconsistencies between observed data values and the formal frame given by the data structure or metadata	<ul style="list-style-type: none"> • Impossible codes for categorical variables • Values outside the allowed range for continuous variables • Data outside the time frame of the study • Unexpected missing values or missing patterns • Number of repeated observations for a subject differs from the planned number • Consecutive dates which are out of order • Unreasonable time differences
Inconsistencies in the reporting of values for a single variable	<ul style="list-style-type: none"> • Large gaps in the distribution of a continuous variable indicating a technical error, e.g. change of the measurement unit in the data collection process or a use of different systems or measurements (e.g. metric vs imperial, or a different lab assay) • Outliers explainable by entry errors (e.g. switches in labels) • Inconsistent use of data formats • Inconsistent use of upper and lower case letters, or typographical variants of the same term
Indications of typical mistakes in the data collection or entry	<ul style="list-style-type: none"> • Duplicate records (indicating double entry) • Partial duplicates (indicating unintended copy and paste) • A reversal of digits in non-matching key variables

Source: Huebner et al, 2018.¹⁵

Identifying the group of interest and assuring data capture

Explicit definition of the target population and the objectives of collecting patient-reported measures from that group is a key step in formulating an analytic plan. Options for a target population include 'all patients' or various clusters of patients, such as those:

- who consulted a particular clinician
- who went to a particular hospital, practice or clinic
- with a particular disease
- in a particular social group

- who received a particular treatment (plus matched controls for implementation studies, (e.g. key Leading Better Value Care cohorts, Figure 5).

Definition of the target population informs decisions about whether to adopt a census or sampling approach, selection of survey instrument or item, mode and method of data collection, and appropriate analyses, inferences and defensible conclusions.

Figure 5: Leading Better Value Care and Integrated Care cohorts – key considerations for patient-reported outcome measures



Assessing ability to participate amongst the target population

Membership in culturally and linguistically diverse groups, disability, cognitive impairment and low literacy levels can often be important variables in differentiating those who receive and respond well to treatment from those who do not. Patients in these groups may experience different health outcomes because of disparities in, or barriers to, care. However, these groups can often be excluded, either explicitly or implicitly, from patient-reported measure collection.

Data analytic plans therefore seek to assess coverage (proportion and type of population reached), effect of mode of questionnaire administration, quality of translation, patterns of non-response, opting out and barriers to participation that may bias results as a result of this type of exclusion.

Assessing patterns of questionnaire non-response

Evaluating the amount of, reasons for, and patterns of missing data is crucial as part of analytic plans. Some common strategies to evaluate non-response bias include:

- conducting an abbreviated follow-up survey with initial non-respondents
- comparing characteristics of respondents and non-respondents
- comparing respondent data with comparable information from other sources or linked data
- comparing on-time vs late respondents.⁷

Efforts to accommodate the needs of patients with diverse linguistic, cultural, educational, and functional skills, through the use of proxies, or flexibility in methods and modes of questionnaire

administration can lead to measurement error and bias – and may impact response rate, reliability, and validity. The risk of introducing measurement error is generally thought to be outweighed by the risk of excluding significant segments of the population. Size and direction of bias can be estimated from samples with simultaneous self and proxy report.⁷

As well as questionnaire (or unit) non-response, item non-response (one or more missing answers within a questionnaire) can also bias analyses, findings, and conclusions or recommendations. Patterns of item non-response are assessed within data quality assessment processes (see *Identifying the group of interest and assuring data capture* – page 15).

A note on ethics

With the burgeoning use of patient-reported measures, individuals will increasingly belong in a range of target populations and subgroups. They will potentially be asked frequently to complete surveys. Increases in survey participation and potential secondary data sources pose some threat to the privacy and confidentiality of respondents, and could result in public concern over privacy and withholding of data.*¹⁶

The NSW Health PRM program seeks to ensure accessibility. Surveys can be answered in languages other than English, translated measures have been assessed for cultural validity, carers or proxies can assist in completion, and text to voice options are available for people with low literacy or vision. Work continues to be co-designed with clinicians, consumers and advocacy groups.

* The NSW Health Legal and Regulatory branch endorsed the HOPE program's consent and appropriate primary and secondary uses of data. Ethics were considered in that document and in the PRM Data Governance and Management Framework.

Measuring outcomes and sensitivity to change

It is important to differentiate between patient-reported data and patient-reported outcomes. Much of the information collected using platforms such as HOPE relates to point of care measures of health status, symptoms or quality of life. To truly reflect outcomes, measures must either capture two or more time points – pre- and post- delivery of care – or be measured at a specific time compared to the provision of care.

To be clinically useful, patient-reported outcome measures must demonstrate sensitivity to change, both when individuals improve and when they deteriorate but not to be over-sensitive to 'normal' fluctuations.¹⁷

One way to assess clinical meaningfulness in outcome measurement is to determine the minimally important difference. This is defined as 'the smallest difference in score in the outcome of

interest that informed patients or proxies perceive as important, either beneficial or harmful, and that would lead the patient or clinician to consider a change in management'.¹⁸

It is also important to assess floor and ceiling effects. These can be problematic as they limit the ability to detect meaningful growth or deterioration.¹⁹

Response shift refers to a change in the meaning of a patient-reported measure over time, which can threaten the validity of the measured quality of life or symptoms as an outcome of care (Figure 6). There are three main types of response shift: recalibration, reprioritisation and reconceptualisation (Box 1).

Box 1: Types of response shift

Recalibration – A change in an individual's internal standards of measurement. This may involve a change in the reliability of a score or a change in the measurement scale (e.g. a value of '3' on a five-point Likert scale at one time may not have the same meaning at a later time point). Recalibration can occur when patients become accustomed to living with specific symptoms or functional status.

Reprioritisation – A change in an individual's values pertaining to the construct of interest. For example, a change of relative importance of items or domains contained in the patient-reported outcomes instrument. Reprioritisation can occur as a result of shifts in life goals and objectives, disease progression, or development of new comorbidities. For example, for a person with a progressive life-limiting illness, someone who previously put a lot of emphasis on physical fitness as a means to enable active socialising, deprioritises that, replacing it with the closeness of relationships (which do not require physical fitness). In this scenario, the person no longer gives such a low rating to lack of physical function.

Reconceptualisation – The construct being measured has fundamentally changed over time (e.g. a person's internal conceptualisation of health may change during the course of an advancing life-limiting illness).²⁰

Source: Sawatzky et al, 2017.²¹

Response shift has historically been considered to pose a threat to time series validity, reliability, and responsiveness. Without a robust assessment of potential response shift, it is difficult to ascertain whether a change in patient-reported data is because of response shift, an effect of treatment, both, or whether a 'real' shift has been obscured by response shift.

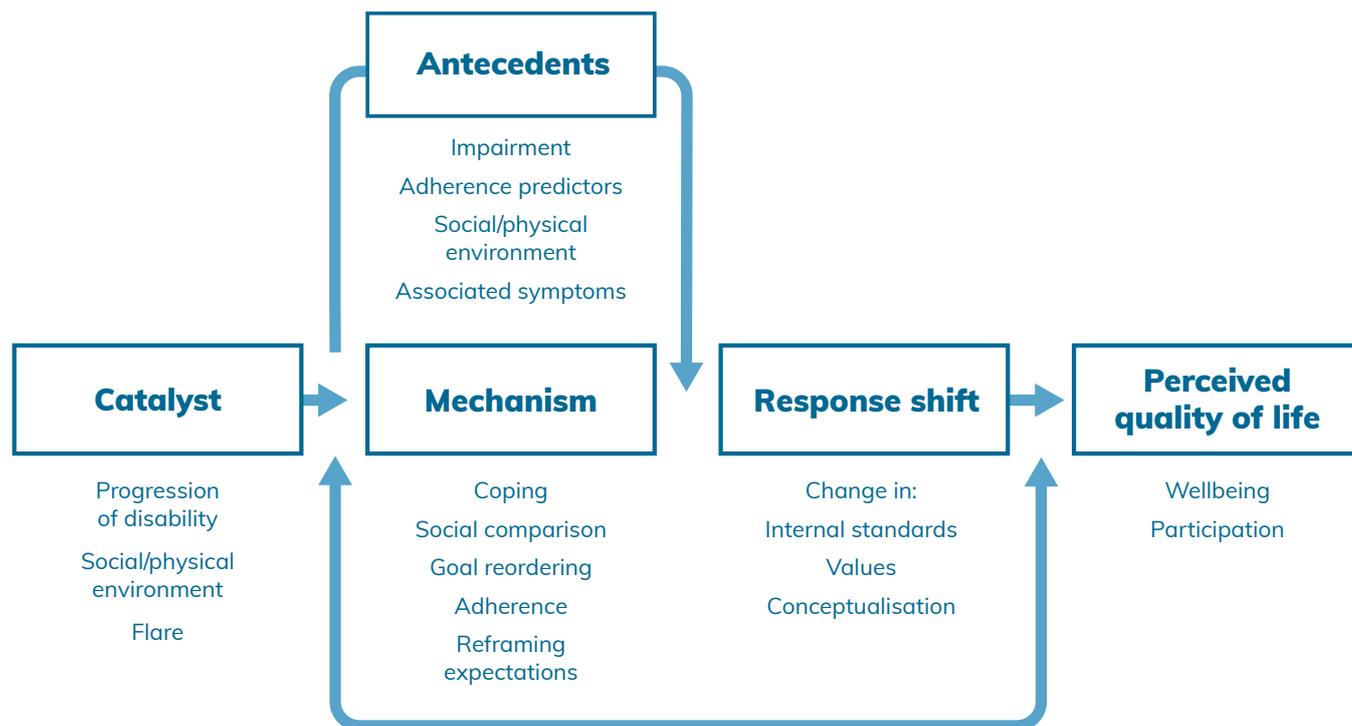
Increasingly however, response shift is starting to be considered not to be always an error but instead may reflect the true trajectory of patient recovery.

A variety of statistical methods have been used to examine response shift. For example, factor analysis has been used to detect reconceptualisation and reprioritisation by assessing changes in factor structure and factor loadings over time, respectively.

Other statistical approaches include the use of growth curve modelling with structural equation modelling, analysis of residuals, and multivariate multilevel modelling.

The halo effect is a cognitive bias to be considered in survey analyses. It refers to the idea that a person or attribute considered highly (or lowly) valued in one aspect becomes highly (or lowly) valued in some other aspect unrelated to the original assessment. When this happens, people tend to assess all constructs according to their perception of the valued construct (e.g. because I can walk well, I will assess all other aspects of my health highly).

Figure 6: Response shift



Source: Faigle, 2018.²²

Measuring outcomes and sensitivity to change

Time series or longitudinal analyses require validated rules of attribution and established processes for dealing with missing data. These are essential before using data for reflective practice, evaluation or predictive purposes.

Attribution and time of data collection

Patients who complete a questionnaire before their appointment with a clinician (either at home or in the waiting room) cannot reflect on the impact of what occurred at the appointment – they can only provide information about their quality of life, functioning or symptoms preceding receipt of care. The impact of care received at a specific appointment can only be quantified at some point after the encounter. A patient-reported measure collected during an encounter is not an outcome of that encounter. It can however be an outcome of a previous encounter in the same or in a different clinic or setting.

For emergency admissions, patient-reported measures are often only available post encounter. Without the pre-encounter measurement, analyses are at risk of confounding by indication – where the measured outcome reflects the presenting complaint rather than the care received. One way to address this is to assess patient-reported measures against expected outcomes as defined by aggregated, risk adjusted data informed by clear understanding of patient trajectories.

Missing data

Missing data are a significant threat to validity in longitudinal analyses. Statistically this can reduce precision (wider confidence intervals) and power to detect statistically significant differences. More importantly, when there is an interaction between patients' health status and the missing data, there is the potential for bias in estimating both between-group (i.e. evaluations) and within-group effects (i.e. changes over time).

While missing data pose significant challenges, it is still possible to perform a valid and sensible analysis. In developing an appropriate analytic response, the first step is to ascertain whether missing data are missing completely at random (MCAR), missing at random (MAR), or missing not at random (MNAR).^{7,23}

- Data missing completely at random (MCAR) are those where the probability of data being missing is unrelated to a patient's outcome. For example, a clinic forgets to administer the questionnaire.
- Data missing at random (MAR) reflect a systematic relationship between the probability of missing values and some aspect of the observed data, but not the missing data items themselves. For example, males are less likely to fill in a depression survey but this has nothing to do with their level of depression, after accounting for their gender.
- Data missing not at random (MNAR) are deemed 'non-ignorable' and reflect a relationship between the probability of a value being missing and its values. For example, sickest people are least likely to complete follow-up surveys.

Missingness can also be categorised as monotone or intermittent. If a patient moves away or dies, their data from a certain point onwards will be unobserved, this is termed monotone missingness, and data are considered to be censored (Table 9).

The question of how to deal with patients who die requires particular care. Some research studies impute a score of 0. While this is reasonable for some scales where 0 is explicitly anchored to death (e.g. utilities, functional well-being), it does not make sense for others such as symptom and physical scales, where a 0 could mean that the deceased patient is experiencing severe nausea, vomiting and pain.²⁴

Intermittent missingness is when an outcome is unobserved at one assessment but is observed at a following assessment, and this is more typical in patient cohorts with chronic conditions.

There are established methods to deal with data 'missing at random' such as maximum likelihood methods, multiple imputation and extensions to generalised estimating equations.²³ However, this is an underdeveloped area in the literature.

Inappropriate methods for handling missing patient-reported outcome data in longitudinal randomised controlled trials have been well documented.²⁵ The use of improper methods for missing data (e.g. simple interpolation and

complete case analysis) are a top concern of journal editors in psychiatry, psychology and public health;²⁶ and reporting on how missing data are handled and any sensitivity analyses is poor.^{23,26}

Further complexity is added as survey instruments change over time. In order to accommodate changes and maintain the ability to undertake longitudinal analyses, updated surveys are formulated in a way that is backward compatible, or previous reports and historical data series are updated to align with the new survey.

Table 9: Missing data, censoring and truncation

	Censoring	Truncation
Static data sets	Where the value is only partially known (i.e. it exists but is beyond our ability to detect it precisely (<5ppm or >\$250,000))	
Longitudinal data sets	<p>Right censoring occurs when a subject leaves the study before an event occurs, or the study ends before the event has occurred. For example, consider patients in a clinical trial to study the effect of treatments on stroke occurrence. The study ends after 5 years.</p> <p>Two types of independent right censoring:</p> <p>Type I: completely random dropout (e.g. emigration) and/or fixed time of end of study no event having occurred.</p> <p>Type II: study ends when a fixed number of events amongst the subjects has occurred.</p>	<p>Right truncation occurs when the entire study population has already experienced the event of interest (e.g. a historical survey of patients on a cancer registry).</p> <p>Left truncation occurs when the subjects have been at risk before entering the study (e.g. life insurance policy holders where the study starts on a fixed date and the event of interest is age at death, i.e. who died before that date?).</p>

Source: Meyer, J. [n.d.] and University of Oxford Dept of Statistics, 2007.³⁹⁻⁴⁰

Additional confounders to consider in evaluation

The use of patient-reported measures for evaluation and policy purposes requires careful exploration of potential bias by indication and by case mix.

Confounding by indication

When an exposure (e.g. an episode of care) appears to be associated with an outcome, the outcome may, in fact, be caused by the indication (or disease) for which the exposure was used, or some factor associated with the indication. The apparent association between the exposure and the outcome is then said to be confounded by the indication, which is the true cause of the outcome (Figure 7).

There is a broad range of potential confounders to consider. Before undertaking evaluations, preparatory work (such as univariate analyses) can assess whether to adjust for different variables, such as:

- age and sex
- underlying biological, psychological and social mechanisms that lead to specific outcomes
- the relationships between potential confounders and both intervention (care delivered) and patient-reported outcome variables
- appropriate analyses, study designs and statistical methods that reduce or eliminate confounding by indication.²⁷

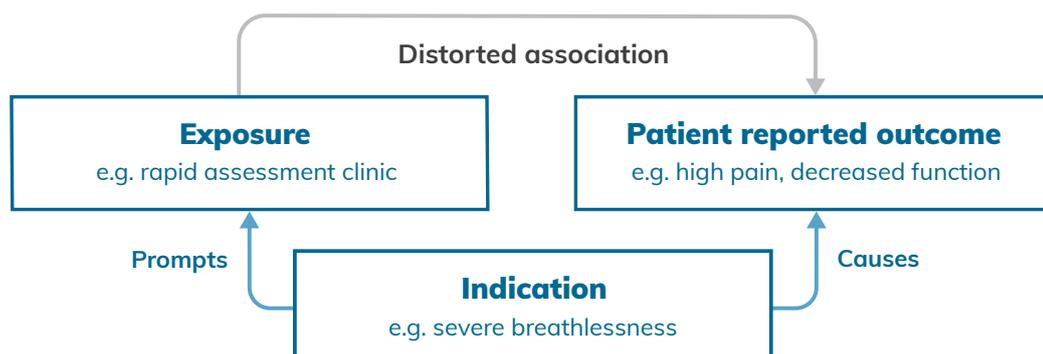
Triangulation of various data sources is a way to assess confounding. Potential data sources include patient-reported experience measures and administrative, social services and primary care data repositories.

Case mix, risk adjustment or stratification approaches ensure fair and accurate comparisons.²⁸ Factors such as comorbidities, severity of underlying disease, frailty scores and socioeconomic status, are established risk adjustment variables to consider.²⁹

Beyond standard variables, patient-reported data evaluations can consider stratifying or adjusting for subtypes of disease, e.g. subtypes of attention deficit hyperactivity disorder (ADHD), (Figure 8a); externalities, such as the weather, access to ancillary social services, such as National Disability Insurance Scheme, and social and psychological factors such as significant life events, e.g. chronic obstructive pulmonary disease (COPD) and the weather (Figure 8b); and patient resilience, e.g. post-surgical outcomes and psychosocial characteristics (Figure 8c).

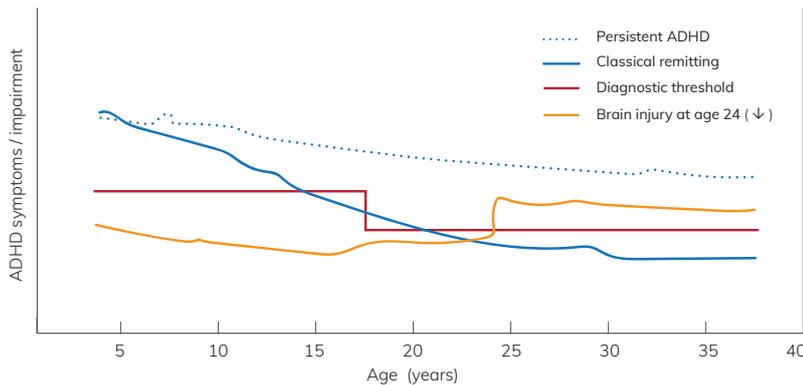
Sensitivity analyses can clarify risk adjustment approaches for different purposes. For example, socioeconomic status may be an appropriate risk adjustment variable when evaluating clinician or unit performance. It may be misleading, however, when evaluation is at a system level.

Figure 7: Confounding by indication



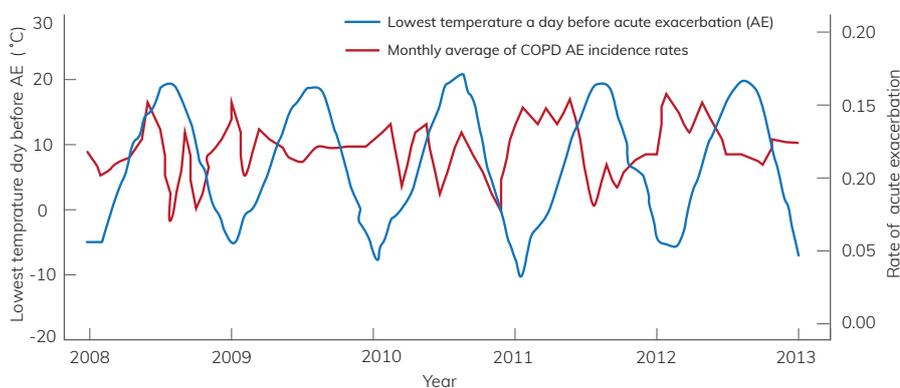
Adapted from: Aronson et al, 2018.³⁰

Figure 8: Illustrating the importance of case mix in evaluation



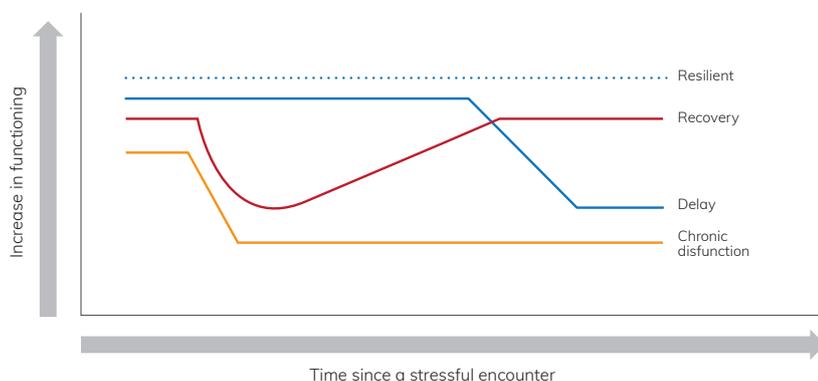
a. Disease subtypes with a different trajectory

This study illustrates variation within a single disease – ADHD and symptoms. Evaluation across units using patient-reported outcomes would require identification of subtype and stratification or risk adjustment.³¹



b. Association between ambient temperature and COPD symptoms

This study demonstrates the relationship between temperature and COPD symptoms. This means that before patient-reported symptom control is used to evaluate clinician or hospital performance, ambient temperature weather should be taken into account.³²



c. Psychosocial change in post-surgery recovery – patient characteristics as potential confounders

This study illustrates psychosocial changes following surgery. Evaluations of clinician or hospital performance could be biased by different distribution of patient resilience across settings and units.³³

Confounding and patient trajectories

Meaningful measurement and assessment takes into account the differences in patient characteristics, disease trajectories and where a person sits on their disease trajectory at a particular point in time. This is a complex task, complexified by several factors.

Many chronic diseases (e.g. COPD, chronic heart failure (CHF)) have a relapsing-remitting pattern and if this is not considered in interpretation of patient-reported time series data there is a risk of misinterpretation. For example, there are well understood patterns of patient reported function (Figure 9a) that shows a typical pattern of relapsing and remitting disease.

If a 'pre-' treatment measurement was taken at time 1 and a 'post-' treatment measurement was taken at time 2, the measurement of change would be confounded by regression to 'normal state'. There is a real risk that the change in function would be attributed to the care provided rather than be interpreted as a consequence of the expected course of the disease.

Trajectories are important to consider not only in time series analyses.

Evaluation of performance for CHF clinics for example require an assessment of expected outcomes for patients, given their position in the course of their disease (Figure 9b). While unadjusted PRM results would suggest Patient B was faring better or had received better care than Patient A, consideration of patients' position on expected disease trajectory would suggest such differences were not clinically or materially significant.

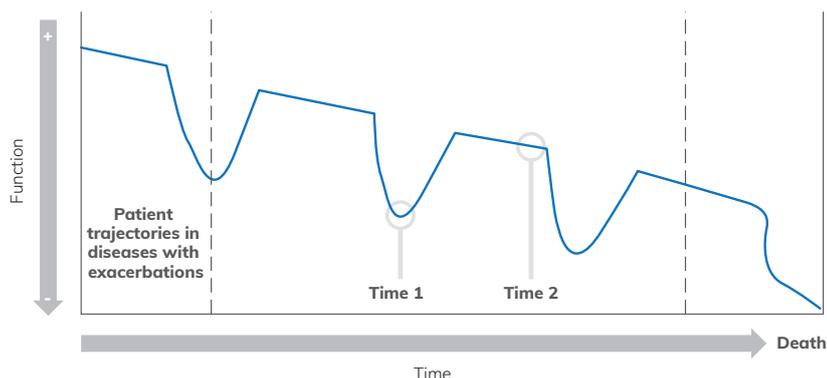
Further, not all patients with the same disease or procedure follow an identical trajectory (Figure 9c).

Disentangling disease trajectories and expectations about outcomes at different points along those trajectories requires considerable analytic acumen. Great care is needed in determining whether comparisons are fair and meaningful before patient-reported outcome data are used to reflect on clinician, unit, ward or hospital performance.

Before data can be used for evaluation and policy, the following steps are recommended.

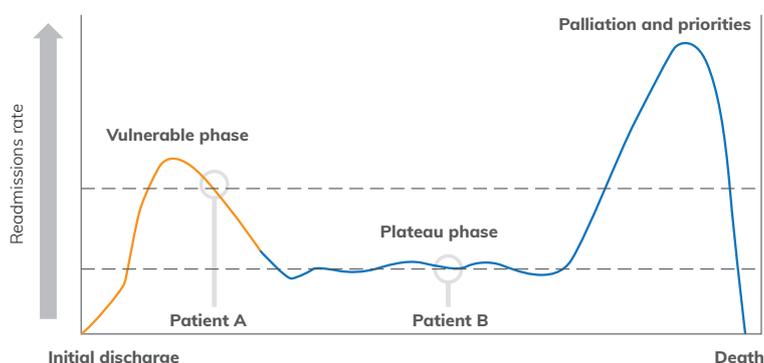
- Map patient utilisation history
- Map place of measurement and place of attribution for each measure
- Assess how to attribute when there are multiple teams involved
- Establish and validate expected patient trajectories to use as a basis for interpreting patient-reported outcomes and evaluating performance
- Define timing for treatment, measurement and attribution for different conditions
- Use of linked data to strengthen attribution
- Use of propensity matching approaches
- Define decision rules around multiple visits and intervals
- Investigate halo effect –where a response or outcome in one aspect of care influences responses in other aspects.

Figure 9: Illustrating the importance of understanding underlying patient trajectories in evaluation



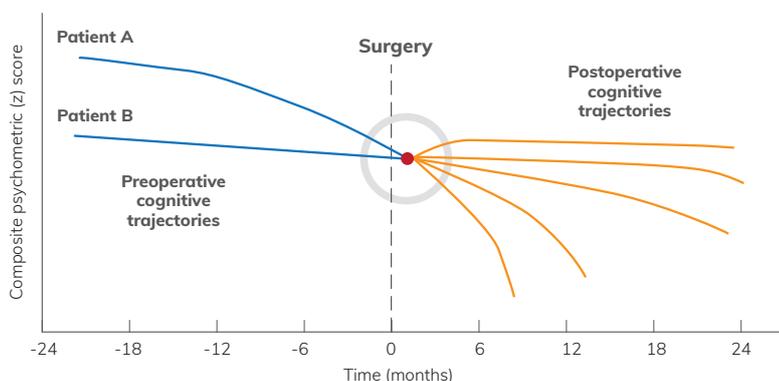
a. Expected patient trajectories and regression to a norm

A crude comparison of patient-reported measures at time 1 and 2 would suggest improvement following receipt of care, when the change may in fact reflect a return to normal state, which would have occurred without any treatment.³⁴



b. Patients at different points of the disease trajectory

This figure illustrates the care needed to make comparisons between clinicians, clinics or hospitals for CHF patients – if units have different proportions of stage 1 and 2 patients. Observed differences in outcomes may be spurious.³⁵



c. Variation in post-operative trajectories

This study illustrates a range of potential postoperative trajectories. Measured outcomes should take into account expected trajectories.³⁶

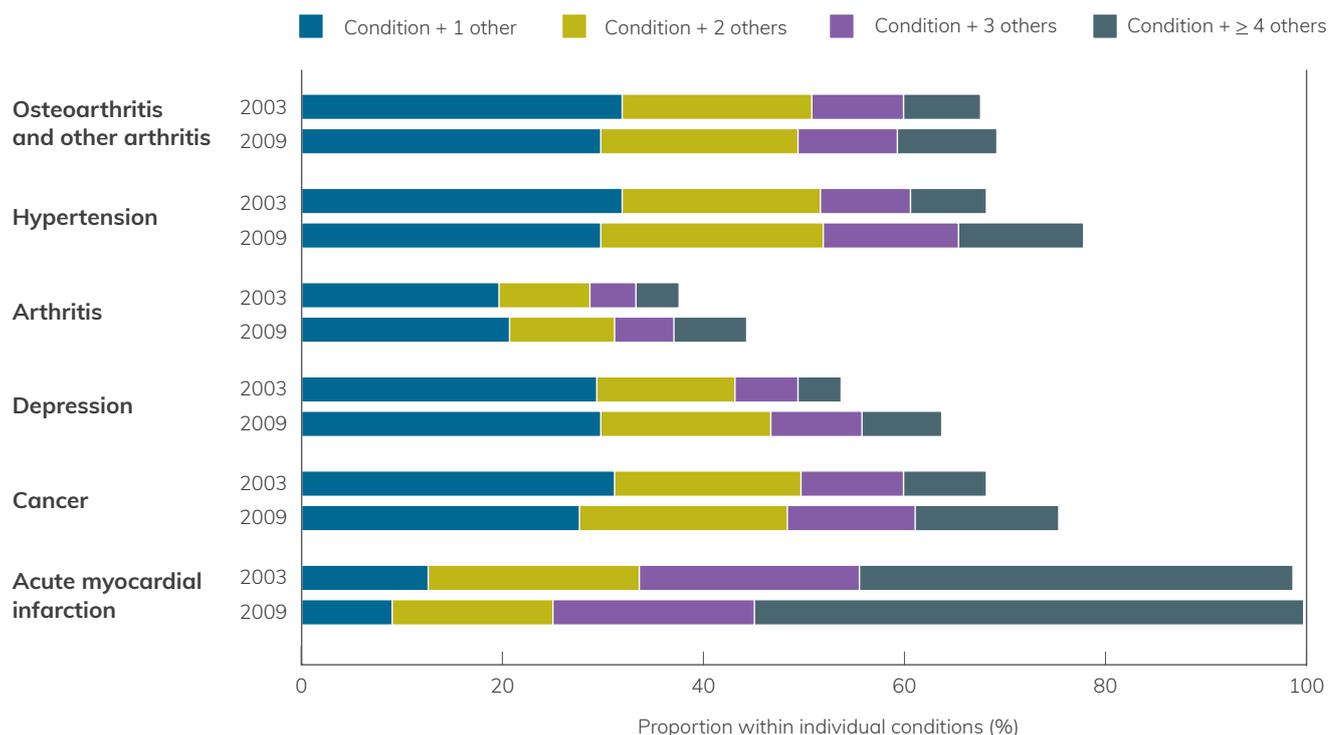
Confounders – complexity

In terms of complexity of care, there are two key dimensions to consider before undertaking evaluation analyses.

1. Case complexity
2. Care pathway complexity.

Case complexity encapsulates multimorbidity, frailty and severity of disease. While risk adjustment techniques often include these factors in isolation, increasingly patients have more than one condition (Figure 10). Analytic assessment is needed to capture the cumulative effects seen in very complex patients.

Figure 10: Patterns of multimorbidity in Ontario, Canada



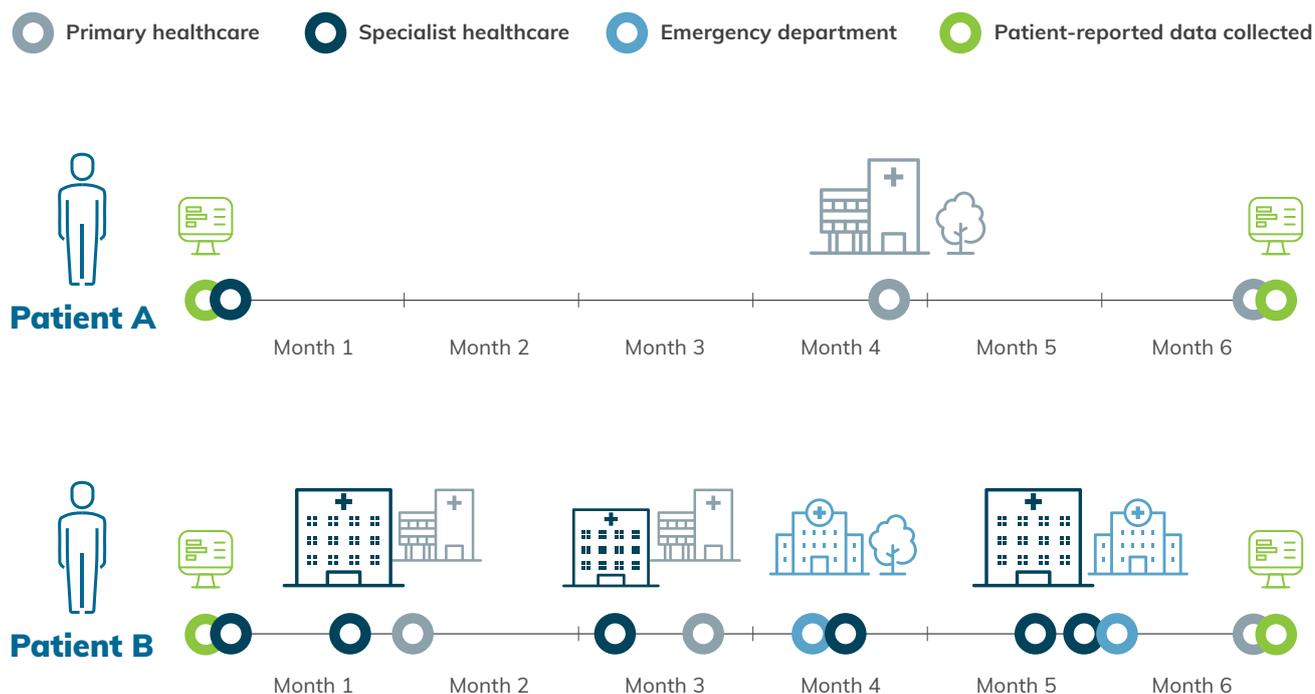
Source: Pefoyo et al, 2015.³⁷

Care pathway complexity refers to the number and variety of care providers. When patients are cared for by multiple services, validated decision rules are required to attribute outcomes or to different care providers.

Interpretation of patient-reported outcomes following a consultant visit requires consideration of the patient pathway preceding that visit (Figure 11).

The treatment of long term conditions generally depends on both primary and secondary care, and therefore whole health economies may be the appropriate entity to consider. However, attribution at such an aggregated level can dampen individual clinician ownership of any outcomes, or ‘felt need for change’ and improvement efforts.

Figure 11: Examples of different patient pathways



Metadata

Metadata is 'data about data'. Metadata derived for PRMs is important for technical and IT system management or development; but it can also be used in more clinically and operationally meaningful analysis.

There are three main types of metadata.

- **Business metadata:** provides the meaning of data, by defining terms in everyday language without regard to technical implementation. It focuses on the content and condition of the data and includes details related to data governance.
- **Technical metadata:** provides information on the format and structure of the data as needed by computer systems. Examples include physical database tables, access permissions, data models, backup rules, mapping documentation, and data lineage.
- **Operational metadata:** describes details of the processing and accessing of data. Examples of operational metadata include job execution logs, data sharing rules, error logs, audit results, various version maintenance plans, archives and retention rules.

Why is metadata an important consideration in an analytic plan?

Information generated from metadata can help inform interpretation of results. For example, differences in the mode and method of data collection may need to be considered in evaluation or time series assessments.

Within the HOPE system, patient-reported data on health status, symptoms and quality of life factors are collected prior to appointments.

There is some evidence that patients may experience anxiety in completing PROMs in clinical settings before their appointments. Similarly, a possible lack of privacy when completing PROMs in waiting rooms or similar circumstances.⁷

Follow-up measures are often collected from home before or between medical appointments. Any bias associated with location of survey completion should be assessed. The use of 'proxy completers' is also important to note and assess and is a critical analytic use of metadata.

Operational metadata are relevant for a range of analytic purposes (Table 10).

Of particular value are date and time, stamps of survey start and completion, the number of surveys and interactions with the technology platform, system performance and response time. These data can be considered for risk adjustment or to inform algorithms for attribution of patient outcomes.

Table 10: Operational metadata

Operational metadata categories	Examples
Physical features of metadata	Size of tables and surveys, the numbers of records for each survey, maximum and minimum record sizes if the records are of variable length
Record manipulation metadata	Date and time stamps, when the record is created, last updated, who has accessed and modified the record and the results or output of the last modification
Management metadata	History of surveys and data within surveys, stewardship information and responsibility matrices
Data practitioners	Total number of staff accessing locations, surveys, data, reports and tracking the objects they access
Security and access metadata	The owner of the metadata, data custodianship model, who may access the data and with which permissions (per <i>Data Governance and Management Framework</i>)

Phased approach – proposed timelines

	Primary use (raw data used at the point of care)	Secondary use (analytics for real-time, to support reflective practice, system monitoring and policy)	Expected timelines and assigned responsibility
Phase 1 Data quality	<p>Use PRM data within HOPE data to:</p> <ol style="list-style-type: none"> 1. Assess and document participation rates by cohort, site and in relation to primary care provider 2. Review and document completeness and accuracy of all fields 3. Establish processes where information from (1) is used to improve data quality across cohorts and sites 4. Commence development of metadata in Health Information Resources Directory (HIRD). 	Does not commence until phase 1 and 2 are complete, and results available to inform analytics.	<p>1st edition, Analytic Plan for patient-reported data within HOPE.</p> <p>This work is currently conducted for non-PRMs statewide information systems by System Information and Analytics (SIA) at the Ministry of Health. At the same time, the Bureau of Health Information (BHI) does this for all current statewide experience data. Assignment of this core responsibility needs to be discussed, determined and recommended to the Steering Committee.</p>
Phase 2 Descriptive analyses	<ol style="list-style-type: none"> 1. Cross sectional and longitudinal assessments and documentation using descriptive statistics to: <ol style="list-style-type: none"> (a) further understand participation rates and attrition across cohorts, hospital sites and primary care, (b) further understand the completeness and accuracy of data in all fields, and (c) consider appropriate integration and linkage with other datasets. 2. Establish processes where information from (1) is used to improve data quality across cohorts and sites, and where appropriate, develop metadata in HIRD. 	Does not commence until phase 1 and 2 are complete, and results available to inform analytics.	<p>1st edition, Analytic Plan for patient reported data within HOPE.</p> <p>This work is currently conducted for non-PRMs statewide information systems by SIA. At the same time, BHI does this for all current statewide experience data. Assignment of this core responsibility needs to be discussed, determined and recommended to the Steering Committee.</p>

	Primary use (raw data used at the point of care)	Secondary use (analytics for real-time, to support reflective practice, system monitoring and policy)	Expected timelines and assigned responsibility
Phase 3 Advanced descriptive and multivariate analyses	At a minimum, develop an implementation plan about how PROM information will be provided back to clinical groups, hospital sites and primary care, so that a target date can be set to implement that plan and commence real-time collection of PROMs via HOPE. Integration into the ROVEAPP.	TBD	2nd edition, Analytic Plan for HOPE In relation to analyses for primary use, BHI does this for all current statewide PRMs data. Assignment of this core responsibility needs to be discussed, determined and recommended to the Steering Committee.
Phase 4 Predictive analytics	TBD	TBD	2nd edition, Analytic Plan for HOPE

Source: BHI and working group

Dissemination of data and analyses

To support the use of PRM-based data and analyses by decision makers, accessible and user-friendly formats are required. For each phase shown here, formats and platforms for dissemination to various audiences should be developed and user tested.

Personas



Persona 1: Clinician

Dr Jaq Jones is a respiratory physician based at a teaching hospital in metropolitan Sydney. Each patient with COPD who attends Dr Jones' clinic completes a PROMIS-29 and a COPD Assessment Test while they are seated in the waiting room. The results are captured electronically in the Health Outcomes and Patient Experience (HOPE) system.

Direct interaction with patient-reported measures

Real-time use

- Assessment of current treatment plans with patients and their carers
- Shared decision making about future treatment regimes
- Assess health and IT literacy
- Identification of emerging issues important to patients.

Monthly reviews

- An overview of results (and historical data) for all patients seen each month
- The clinic's results, benchmarked against other clinics.

Use of patient-reported data is supported by

Local support teams (PRM leads) provide assistance in extracting and viewing data from HOPE, and capability building in 'how to' talk to patients about the use of patient-reported data in informing and guiding care.

A quick guide advises how to interpret patient-reported data (e.g. scoring methods; normal ranges; minimal clinically important differences; timing of data collection).

Do

Real-time use

- A sense check for face validity of patient-responses (e.g. confirm that a high score for pain is accurate if a patient seems well)
- Consider results alongside other clinically relevant data, such as for COPD patients, the FEV1 test (forced expiratory volume for one second).

Monthly reviews

- Consider results alongside other clinically relevant data such as utilisation, registry and audit data survey results
- Be aware of the impact of potential confounders – physical, psychological, social factors
- Consider completion rates in light of health and IT literacy.

Do not

- Do not over-interpret numeric changes in health status or symptom metrics; do not rely on item score changes - instead use analyst validated macros to interpret change
- Do not consider fewer than three time points as a series (be aware that multiple time points require careful interpretation, in particular how to deal with missing data, and the potential effect of response shift)
- Do not use or share data that falls outside the *PRM Data Governance and Management Framework*.

Unknowns

- How to account for patient survey fatigue?
- How to optimise and standardise data collection time points with respect to key events, e.g. diagnosis, treatment, follow-up?



Persona 2: Nurse unit manager

Lauren is a nurse unit manager of a medical ward which often cares for patients CHF, COPD and diabetes. As these conditions are part of the Leading Better Value Care program, patients are surveyed and results are captured electronically in the Health Outcomes and Patient Experience (HOPE) system.

Direct interaction with patient-reported measures

Real-time use

- Provide support and encouragement for patients to complete the survey(s) and emphasise how they can be used to improve quality and value.

Monthly reviews

- Ward reports based on clinically and statistically validated data summaries support quality improvement meetings.

Use of patient-reported data is supported by

- Local support teams (PRM leads) provide assistance in data entry and ward summary reporting from the HOPE system, and capability building in 'how to' talk to patients about the use of patient reported data in informing and guiding care
- A quick guide advises how to interpret patient reported data (e.g. scoring methods, normal ranges, minimal clinically important differences, timing of data collection).

Do

- Understand the potential contribution of patient-reported data to shared decision-making and quality improvement, and encourage its collection and use
- Seek assistance from local PRM leads and PRM administration functions for assistance with data entry, data extraction and accessing results from HOPE
- Learn about how to appropriately use aggregated data to review ward level performance
- Consider whose performance shapes the patient-reported data, particularly where care is provided by multidisciplinary teams.

Do not

- Do not over-interpret numeric changes in health status or symptom metrics when assessing unit or ward performance; do not rely on item score changes - instead use analyst validated macros to interpret change
- Do not make simple comparisons across different units without using methods that take account of patient trajectories and journeys
- Do not use or share data that falls outside the *PRM Data Governance and Management Framework*.

Unknowns

- How to support clinical staff to better understand aggregate ward level data and use in parallel with other available data e.g. utilisation history, etc.
- Whether survey fatigue will set in, leading to increased missingness.



Persona 3: Data analyst

Dipak is a data analyst who is familiar with the NSW Health data assets and has considerable experience using SAS, SPSS and Excel software to analyse administrative and survey data. He is responsible for supporting clinicians and managers in the local health district in their use of PRM data and providing quarterly reports. He has limited experience with patient-reported outcome data.

Direct interaction with patient-reported measures

- Extraction of patient-reported data and metadata from the Health Outcomes and Patient Experience (HOPE) system through ROVEAPP or Enterprise Data Warehouse (EDWARD)
- Data cleaning and assurance checks (missing data, duplicates, logic checks)
- Operationalisation of the *PRM Data Governance and Management Framework*
- Development of analytic plans for local patient-reported data assessment and reporting, as outlined in this report.

Use of patient-reported data is supported by

- The *NSW Health Data Governance Framework*⁴²
- District data stewards and data privacy officers
- Policy documents that endorse patient reported data collection tools for use in NSW Health
- Experts in patient-reported data analytics, at the Ministry of Health
- Training
- Community of practice networks across districts.

Do

- Comply with policies and best practice for data cleaning and quality assurance
- Develop and implement a data analytic plan that assesses and seeks to minimise the potential for bias and confounders
- Actively manage and monitor metadata
- Where required, support exploration of whether additional relevant data exist in other settings and if so, contact data custodians for access
- Be aware of changes in the data analytic landscape and capacity
- User test formats and reports to provide advice to clinicians and managers.

Do not

- Do not triangulate data without a clear clinically validated logic or justification
- Do not aggregate patient results for evaluation without either implementing central protocols, or a thorough assessment of potential confounders, bias and attribution rules
- Do not provide results to end users before appropriate validation and sensitivity testing as outlined in the analytic plan
- Do not interpolate results for missing data without proper assessment
- Do not develop dashboards without a well-developed communication plan and a proper assessment of validity of time series and comparative analyses
- Do not interpret time series data without assessing the potential for bias from response shift or expected patient trajectories
- Do not interpret single point health status or quality of life measures as 'outcomes' as outcomes require pre- and post-care measurement
- Do not interpret patient-reported measures collected in the waiting room as an outcome of the encounter which is about to occur.

Unknowns

- Whether routine triangulation will reveal new insights
- How to appropriately parse out contributions to patient outcomes for patients with multimorbidity and with complex utilisation patterns.



Persona 4: Service manager/decision-maker

Steph Smith is the Director of Performance at a non-metropolitan local health district. Her responsibilities include delivery of Leading Better Value Care. She works at the interface between local clinicians, the LHD Executive and the Ministry of Health's Performance branch. She has three data analysts in her team who undertake all of the activity-based management analyses and routine reporting to the Executive and Board. She is data literate, able to interpret graphs but has limited experience in interpreting patient-reported data.

Direct interaction with patient-reported measures

- Responsible for requesting appropriate data outputs from the analytic team
- Collation and reporting of data to inform executives and decision makers using ROVEAPP or EDWARD
- Delivery of required reports to central agencies.

Use of patient-reported data is supported by

- The *NSW Health Data Governance Framework* ⁴²
- Policy documents that endorse patient-reported data collection tools for use in NSW Health
- Local data analytic team and data steward
- A quick guide advises how to interpret patient-reported data (e.g. scoring methods, normal ranges, minimal clinically important differences, timing of data collection).

Do

- Assure adherence to the *PRM Data Governance and Management Framework*
- Ensure the patient-reported measures used are fit for purpose – i.e. tools and metrics are matched to the measurement objective (informing real time decisions; reflective practice, evaluation, policy)
- Promote awareness of the basis of comparisons – vs a standard, reference value or norm; vs expected results given patient trajectory; vs other patients in cohort; vs other clinicians; vs change over time
- Provide support and resources for foundation data analytics, data visualisation and reporting
- Be aware of changes in the data analytic landscape and capacity.

Do not

- Do not support the use of unadjusted data to make comparisons across providers, units or hospitals
- Do not consider fewer than three observations to be a time series
- Do not interpret patient-reported measures collected in the waiting room as an outcome of the encounter which is about to occur
- Do not use adjustments for socioeconomic status or other wider determinants of health when considering system performance (stratification is clearer where inequity affects outcomes that the system should seek to address and overcome)
- Do not seek to link data without clear purpose and analytic objective.

Unknowns

- How to appropriately parse out contributions to patient outcomes for patients with multimorbidity and with complex utilisation patterns.

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Appendix 1: Leading Better Value Care cohorts and patient-reported measurement tools and schedules

Leading Better Value Care initiative	PROMs tools	PROMs collection points	PREMs collection points
Management of osteoarthritis / Osteoarthritis Chronic Care Program (OACCP)	PROMIS-29*	<ul style="list-style-type: none"> On commencement of the program Every three months after commencement of the program Upon completion from the program Six-monthly within a primary care setting <p>Note:</p> <ol style="list-style-type: none"> PROM collection points are linked to scheduling of consults, which are guided by the model of care. PROM data will be utilised for real time feedback and review 	<ul style="list-style-type: none"> Every three months whilst in the program Upon completion from the program Six-monthly within a primary care setting
	Hip Dysfunction and Osteoarthritis Outcome Score (HOOS) or Oxford Hip Score (OHS) Knee injury and Osteoarthritis Outcome Score (KOOS) or Oxford Knee Score (OKS)	<ul style="list-style-type: none"> On commencement of the program Every three months after commencement of the program Upon completion from the program Six-monthly within a primary care setting 	
Osteoporotic refracture prevention (ORP)	PROMIS-29*	<ul style="list-style-type: none"> On commencement of the program Six-monthly Upon completion from the program Six-monthly within a primary care setting <p>Note:</p> <ol style="list-style-type: none"> PROM collection points are linked to scheduling of consults, which are guided by the model of care PROM data will be utilised for real time feedback and review 	<ul style="list-style-type: none"> Six-monthly while in program Upon completion from the program Six-monthly within a primary care setting
	Falls Efficacy Scale – International (FES-I)	<ul style="list-style-type: none"> On admission to the ward or identification that they are in the cohort Six-monthly Upon discharge from the inpatient setting Six-monthly within a primary care setting 	

Leading Better Value Care initiative	PROMs tools	PROMs collection points	PREMs collection points
Diabetes high risk foot services	PROMIS-29*	<ul style="list-style-type: none"> • Upon initial presentation to a service • Upon completion from the service • Six-monthly within a primary care setting <p><i>Note:</i></p> <ol style="list-style-type: none"> 1. PROM collection points are linked to scheduling of consults 2. PROM data will be utilised for real time feedback and review 	<ul style="list-style-type: none"> • Six-monthly • Upon completion from the service • Six-monthly within a primary care setting
	Cardiff Wound Impact Schedule (CWIS) Questionnaire	<ul style="list-style-type: none"> • Upon initial presentation to a service • Six-monthly • Upon completion from the service • Six-monthly within a primary care setting 	
Inpatient management of diabetes mellitus	PROMIS-29*	<ul style="list-style-type: none"> • As part of inpatient discharge planning process to identify required support and referrals (e.g. to social worker or psychologist) 	<ul style="list-style-type: none"> • Day prior to inpatient discharge • Three-monthly in outpatient service
	Problem Areas In Diabetes (PAID) Questionnaire Diabetes Distress Scale (DDS)	<ul style="list-style-type: none"> • On commencement of outpatient service • Upon completion from outpatient service • Six-monthly within a primary care setting 	<ul style="list-style-type: none"> • Upon completion from outpatient service • Six-monthly within a primary care setting
Management of chronic obstructive pulmonary disease (COPD)	PROMIS-29*	<ul style="list-style-type: none"> • As part of inpatient discharge planning process to identify required support and referrals (e.g. to social worker, dietitian etc.) • Six-monthly within a primary care setting 	<ul style="list-style-type: none"> • Day prior to inpatient discharge • Three-monthly in outpatient service
	COPD Assessment Test (CAT)	<ul style="list-style-type: none"> • On commencement of outpatient service • Upon completion from outpatient service • Six-monthly within a primary care setting 	<ul style="list-style-type: none"> • Upon completion from outpatient service • Six-monthly within a primary care setting

Leading Better Value Care initiative	PROMs tools	PROMs collection points	PREMs collection points
Management of chronic heart failure (CHF)	PROMIS-29	<ul style="list-style-type: none"> As part of inpatient discharge planning process to identify required support and referrals (e.g. to social worker, dietitian, etc.) Six-monthly within a primary care setting 	<ul style="list-style-type: none"> Day prior to inpatient discharge Three-monthly in outpatient service Upon completion from outpatient service Six-monthly within a primary care setting
	Kansas City Cardiomyopathy Questionnaire (KCCQ)	<ul style="list-style-type: none"> On commencement of outpatient service Upon completion from outpatient service Six-monthly within a primary care setting 	
Renal supportive care (end stage kidney disease)	EQ5D-5L	<ul style="list-style-type: none"> On commencement of the program Six-monthly <p><i>Note:</i></p> <ol style="list-style-type: none"> PROM collection points are linked to scheduling of consults PROM data will be utilised for real time feedback and review 	<ul style="list-style-type: none"> Every six-months
	Integrated Patient Outcome Scale (IPOS) Renal	<ul style="list-style-type: none"> On commencement of the program Six-monthly <p><i>Note:</i></p> <ol style="list-style-type: none"> IPOS collection points are linked to scheduling of consults IPOS data will be utilised for real time feedback and review 	

Leading Better Value Care initiative	PROMs tools	PROMs collection points	PREMs collection points
Adverse events: falls in hospitals	PROMIS-29	<ul style="list-style-type: none"> As part of discharge planning process to identify required support and referrals (e.g. to social worker, dietitian, etc.) On commencement of an outpatient program Six-monthly within a primary care setting <p><i>Note:</i> <i>PROM data will be utilised to inform Falls Collaborative Approach</i></p>	<ul style="list-style-type: none"> Day prior to inpatient discharge Three-monthly through the program Upon completion from the program Six-monthly within a primary care setting
	Kansas City Cardiomyopathy Questionnaire (KCCQ)	<ul style="list-style-type: none"> On commencement of outpatient service Upon completion from outpatient service Six-monthly within a primary care setting <p><i>Note:</i> <i>FES-1 data will be utilised to inform Falls Collaborative Approach</i></p>	
All above	Depression Anxiety Stress Scale (DASS 21)	Optional if clinically indicated	

Glossary

ADHD	Attention deficit hyperactivity disorder
ACI	Agency for Clinical Innovation
Asynchronous	Not occurring in real-time
BHI	Bureau of Health Information
COPD	Chronic obstructive pulmonary disease
Cohort definition	A group of people who share the same characteristics (e.g. diabetes)
Differential item functioning	(DIF) is a statistical characteristic of an item that shows the extent to which the item might be measuring different abilities for members of separate subgroups
EDWARD	Enterprise Data Warehouse
EQ5D-5L	EuroQol five-dimension scale. A standardized instrument for measuring generic health status.
Feasibility	The degree to which an approach or project is achievable and practical
Halo effect	A cognitive bias to be considered in survey analyses
HIRD	Health Information Resources Directory
HOPE	'Health Outcomes and Patient Experience' the patient-reported measures information technology platform
HRQoL	Health related quality of life
LBVC	Leading Better Value Care
Metadata	Data about data
Minimally important difference	The smallest change in a treatment outcome that an individual patient would identify as important and which would indicate a change in the patient's management
Patient-reported experience measures	Ask patients to describe, rather than simply evaluate, what happened during their encounters with health services

Patient-reported measures (PRMs)	Surveys that help us to understand what matters most to patients and to find out if the care we deliver supports the outcomes and experiences that patients expect
Patient-reported outcome measures (PROMs)	Capture information about a patient's quality of life or condition-specific measures (e.g. measuring how diabetes is impacting their life). Responses are directly reported, without interpretation by a clinician or anyone else
PROMIS	Patient Reported Outcomes Measurement Information System - a set of person-centred measures that evaluate and monitor physical, mental, and social health in adults and children
PROMIS-29	The PROMIS-29, a generic health-related quality of life survey, assesses each of the seven PROMIS domains with four questions. The questions are ranked on a five-point Likert scale. There is also one 11-point rating scale for pain intensity.
Recalibration	A change in an individual's internal standards of measurement, an aspect of response shift
Reconceptualisation	The patient's understanding of the construct being measured has fundamentally changed over time
Relevance	The degree to which a measure, approach or proposition pertains to an important aim
Reliability	The degree to which an assessment tool produces stable and consistent results
Reprioritisation	A change in an individual's values pertaining to the construct of interest, an aspect of response shift
Response shift	Refers to a change in the meaning of an individual's self-evaluation over time
ROVE	Register of Outcomes Value and Experience
Standard deviation	A quantity expressing by how much the members of a group differ from the mean value for the group
Synchronous	Occurring in real-time
Validity	The degree to which an instrument, metric or indicator measures what it claims to measure

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